



## Psychological and psychiatric symptoms of terminally ill patients with cancer and their family caregivers in the home-care setting: A nation-wide survey from the perspective of bereaved family members in Japan



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### ABSTRACT

**Objective:** The psychological and psychiatric symptoms of terminally ill cancer patients are highly problematic and have been associated with greater burden among caregivers. Until now, the extent of these problems in the home care setting was unclear.

**Methods:** This retrospective study was conducted as part of a nationwide survey from the perspective of bereaved family members in Japan (J-HOPE3). The bereaved family members rated the symptoms of delirium and suicidal ideation of patients with cancer, and the sleeplessness and depressed mood of family caregivers utilizing home care services in the one month before the patients' deaths. Regression analyses were performed to identify factors associated with caregivers' sleeplessness or depressed mood.

**Results:** Of the 532 subjects analyzed, between 17% and 65% of patients experienced various symptoms of delirium, and 27% suicidal ideation. Among family caregivers, 60% experienced sleeplessness and 35% experienced depressed mood at least once during the week. Caregivers' psychological symptoms were associated with their own poor health status, being the spouse of the patient, and the patients' psychological or psychiatric symptoms. To manage patients' symptoms, 11% of caregivers had consulted psychiatrists or psychologists while another 11% wanted to do so.

**Conclusion:** Psychological problems assessed were common among patients with cancer and their family caregivers in the one month of home care prior to the patient's death. An effective complementary care system, run by home-visit physicians, nurses, and experts in mental disorders, is needed.

### 1. Introduction

Terminally ill patients with cancer suffer from a range of severe problems, including multiple organ failure with severe pain and other physical symptoms, impaired activities of daily living, and

psychological distress. Delirium is frequently observed among dying patients [1–4], and delirium is severely distressing for family caregivers [5,6,7]. Patients also exhibit suicidal ideation as a result of worsening physical symptoms, low performance status, and loss of control of their symptoms [8]. From the study performed in palliative care unit in

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Japan, suicidal ideation among palliative care patients is not rare, and its frequency increases with worsening symptoms [9]. On the one hand, in the palliative care unit in Japan, relatively sufficient medical staffs are available; for example, one nurses per seven patients. On the other hand, in home palliative care, professional resources are limited and care resource for patients depend mostly on family members. Suicidal ideation may disturb continuation of home palliative care. However, its prevalence in the home care setting is currently unclear.

Family caregivers of patients with cancer exhibit psychological distress when facing patients' psychological symptoms at the end of life [10]. Between 4% and 70% of caregivers of patients with cancer experienced psychological distress, including anxiety and depression [11–15]. Anxiety disorders among US caregivers were found to relate to patients' symptoms of confusion or delirium [16], while German patients and family members were both found to have high depression and anxiety levels, which were correlated within the dyad [12]. Other factors influencing caregivers' psychological distress included being female, being a spouse, having financial problems, and social support level [8,11]. Although numerous caregivers demand care from mental health specialists [13,17], there is a lack of professional resources to meet these demands, particularly in rural areas [18]. Some of the previous studies also reported needs of family caregivers from medical staff. The needs were to be with caregivers and to explain the expected course of terminal disease and to relieve the family care burden. However, these results were from cases of hospitalized subjects [6,19]. Furthermore, beyond our lack of knowledge of the prevalence of delirium and suicidal ideation among patients in home palliative care settings, we lack understanding of how such symptoms influence family caregivers. To support patients with cancer and their family caregivers, we thought it necessary to investigate these topics with a large sample from a broad geographic area.

This study was performed as part of a nationwide survey (Japan Hospice and Palliative care Evaluation study: J-HOPE3) assessing the conditions of end-of-life cancer care from the perspective of bereaved family members [20]. Our aims were to determine the prevalence of delirium and suicidal ideation among patients with cancer and determine whether these and other factors influence caregivers' psychological distress.

## 2. Material and methods

### 2.1. Setting and subjects

This was a multicenter questionnaire survey involving family members of patients with cancer who died at home between November 2011 and January 2014. Participating institutions were 22 of the 49 home-based hospice services affiliated with the Japan Hospice Association that agreed to participate. A maximum of 80 bereaved family members per institution were listed as potential participants. We mailed questionnaires to them in May 2014; another questionnaire was sent two months later to non-responding families. Returning a questionnaire was regarded as providing consent to participate. A ballpoint pen was included in the envelope as an incentive to participate. Ethical approval for the study was granted by the institutional review boards of Tohoku University and all participating institutions [20].

Primary physicians identified potential participants according to these inclusion criteria: (1) bereaved family members of an adult cancer patient, (2) aged 20 years or older, (3) utilized home hospice care for three days or longer, and (4) could complete a self-report questionnaire. The exclusion criteria were (1) unavailability for participation, (2) inability to complete the questionnaire (e.g., because of dementia, language difficulties), (3) severe emotional distress (according to the principal physician), and (4) treatment-associated death or death occurred in an intensive care unit (for assessing only end-of life palliative care) [20]. Families were surveyed 6–12 months after the patient's death.

### 2.2. Questionnaire

The questionnaire, which was entirely in Japanese, was developed by the authors via a literature review and interviews and focus groups with 20 healthcare professionals and 5 bereaved family members who were not participants. These items were for a retrospective survey and included both patients' and caregivers' psychological symptoms during the last month before the patient's death. The questionnaire was answered by family caregivers.

#### 2.2.1. Patient delirium

Delirium was assessed using items developed with reference to the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) Scale [21] and the Diagnostic and Statistical Manual of Mental disorders, Fifth edition [22]. Sleeplessness at night and daytime drowsiness are frequent symptoms of delirium; as such, the delirium questionnaire also assessed sleep disturbance. The items were as follows: "How often in the last month has the following occurred? (1) sleeplessness at night, (2) daytime sleepiness and inconsistent talking, (3) disorientation with regard to time and place, (4) being unaware of the situation around him/her or being confused, and (5) illusions or hallucinations." Each symptom had four response options, reflecting their frequency: none, once or twice a month, every week, and every day. As per a previous study [16], responses of "every week" and "every day" were counted as having symptoms worthy of analysis in the present study.

#### 2.2.2. Patient suicidal ideation

Past suicidal ideation was assessed with items adapted from the Japanese version of the Beck Depression Inventory-II [23], which assesses current symptoms of depression. The past suicidal ideation items included "Did the patient talk about these phrases in their last one month before death? 'I have no meaning to live', 'Please hasten my death', and 'I sometimes want to end my life although I will not actually kill myself. Moreover, did patients actually attempt to end their own lives?'" Items were answered as yes or no.

#### 2.2.3. Caregivers' psychological distress and need for professional support

The following questions were asked concerning caregivers' experience with sleeplessness (a frequent symptom of mental disorders) and depressed mood during patients' home care. "Have you experienced sleeplessness at night? If 'yes,' how frequent was it? None, once or twice a month, every week, and every day. And have you experienced depressed mood or diminished interest? If 'yes,' how frequently? None, once or twice a month, every week, and every day." Then caregivers were asked whether they had received medical treatment for these symptoms from psychiatrists. Caregivers were also asked about their need for professional mental health interventions and if they had not received clinical treatment.

#### 2.2.4. Background characteristics

Patients' and caregivers' background characteristics were obtained using the common questionnaire for all J-HOPE3 studies [20]. These data included age, gender, duration of home care, economic status, education, relationship between caregivers and patients. Caregivers were also asked, "How was your physical health status during home care?"; answers of "bad" and "quite bad" were counted as poor.

#### 2.2.5. Home care situation

We assessed factors potentially associated with caregivers' need for the help of mental health experts using items from our previous study [17]. These items included (1) "Because symptoms are not severe during the daytime, doctors or nurses do not understand their severity during home visits," (2) "I felt helpless and guilty because I could do nothing for the patient," (3) "Home-visit doctors and nurses provided no help in symptom management." Items were answered with yes or no.

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